

# ChiPPS E-Journal

*Children's Project on Palliative/Hospice Services*

*Released in collaboration with the National Hospice and Palliative Care Organization*

National Hospice and Palliative Care Organization  
1731 King Street, Alexandria, Virginia 22314  
[www.NHPCO.org/pediatrics](http://www.NHPCO.org/pediatrics)



**ChiPPS E-Journal**  
**Pediatric Palliative and Hospice Care**  
**Issue #53; November 2018**

**Issue Topic: Caring for Adolescents and Young Adults**

Welcome to the 53<sup>rd</sup> issue of the ChiPPS E-Journal. This issue of our E-Journal explores topics related to caring for adolescents and young adults. Professionals and volunteers who work in pediatric palliative/hospice care often are presented with issues involving adolescents and their families, as well as with the young adults who continue to fall within their scope of care. How can professionals and volunteers best respond to such situations? How can they best prepare themselves to be helpful in such encounters? How do things look from the point of view of the adolescents, the young adults, and the family members who find themselves in need of pediatric palliative/hospice care? This issue seeks to provide at least a beginning in discussing such matters.

This E-Journal is produced by ChiPPS (the Children's Project on Palliative/Hospice Services), a program of the National Hospice and Palliative Care Organization and, in particular, by ChiPPS's E-Journal Workgroup, co-chaired by Christy Torkildson and Ann Fitzsimons. Archived issues of this publication are available at [www.nhpco.org/pediatrics](http://www.nhpco.org/pediatrics).

Comments about the activities of ChiPPS, its E-Journal Workgroup, or this issue are welcomed. We also encourage readers to suggest topics, contributors, and specific ideas for future issues. We are currently discussing topics to address in this E-Journal in 2019. If you have any thoughts about these topics, contributors, or future issues, please contact Christy at [ctorkildson@mail.cho.org](mailto:ctorkildson@mail.cho.org) or Ann at [ann@here4U.net](mailto:ann@here4U.net)

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## Issue #52: Caring for Adolescents and Young Adults

Click on the “bookmark” tab on the left-hand side of the PDF document for links to the following articles.

**October**

**p. 5**

### **Scott Newport, Evan’s father**

Scott Newport has authored many poems and essays that have been published in our e-Journal and other publications. Scott, a bereaved father whose son Evan died, has found giving back through the parent mentoring program for Mott Children’s Hospital offers its own special grace. Scott often finds himself working directly with patients, here he shares a glimpse into this most intimate and special work.

### **Death of a Parent during Adolescence: My Personal Journey**

**p. 6**

#### **Alexandra Hawkins, Jeff’s daughter**

When Alec was 14, her father died from cancer. In this essay, her main thesis is that, “If there’s anything I’ve learned in the near-decade since my dad’s death, it’s that grief is a journey. As I’ve grown up, my grief has grown up with me. The pain of losing my father hasn’t gone away, it’s just gotten easier to manage.” As she writes, “Grief has been a rollercoaster of emotions, with ups and downs, sharp twists, sudden drops, and the lowest of lows.” Some things helped, some things didn’t help, and some things might have helped her “to understand that while every grief journey is different, I am not alone.”

### **Our Ultra-Marathon**

**p. 8**

#### **Kathryn Cleberg, Charlie’s mother**

Almost 20 years ago, the author of this article, her husband, and their five children “started on what we anticipated would be a brief and difficult journey” by taking in “A very ill baby boy named Charlie [who] needed a family to love and care for him for what was expected to be the few remaining months of his life.” As the title of this article indicates, “That journey has turned into an ultra-marathon filled with dangerous turns, frightening obstacles, delightful and unexpected gifts, acts of amazing courage, pain, laughter, exhaustion, and countless moments that have taken my breath away.” The courage of everyone involved in this journey is clearly evident in this text.

### **Douglas House, A “Respite” for Young Adults**

**p. 11**

#### **Sister Frances Dominica, Chris Bloor, and Mathew O’Sullivan**

Helen House, the world’s first children’s hospice, opened in Oxford, England, in 1982. By 20 years later, many of the children being served had become young adults and it was decided to open Douglas House to offer “respite care, symptom control, stepped discharge from hospital, end-of-life care, and long-term family support. Fundamentally, it was an attempt to encourage and enable these young people between the ages of 16 and 35 to live life to the fullest, however long or short that life might be.” In this article, the founder of Helen House, a nurse who has worked at Douglas House for over 9 years, and a “guest” who has received respite care at Douglas House since 2006 each point out what is unique about such a facility, its distinctive philosophy of care, and why it is needed.

### **What We’ve Learned about Adolescents and Young Adults Who are Grieving**

**p. 14**

#### **Terri L. Bowling, MS, CT, ACTP**

This article describes how a children’s grief center expanded its services to meet the needs of young adults in the 18-30 age group. Boxes describe the feelings these grieving young adults have shared, as well as the challenges and changes they experienced after the death in the midst of their busy life styles, and their strategies for coping.

### **Adolescents’ Use of Social Media and Digital Technology to Cope with Life-Threatening Illness and Loss: What Parents and Supportive Adults Should Know**

**p. 18**

#### **Carla J. Sofka, PhD, MSW**

Contemporary adolescents are said to be “digital natives,” by contrast with many adults who are “digital immigrants.” Because contemporary adolescents use social media and digital technology on a daily basis, it should be no surprise that these tools are prominent in ways in which such adolescents cope with life-threatening illness and loss. This article offers a primer for parents and supportive adults who wish to learn about and be helpful to contemporary adolescents in navigating the digital universe. The article



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covers such topics as death notification, gaining emotional and informational support, resources for memorialization and creative expression of grief, continuing bonds with the deceased, funeral selfies, and digital survivor advocacy. The article closes with a list of eight specific suggestions for parents and supportive adults.

### **Critical Decision-Making for Adolescents with Life-Threatening Illnesses** p. 28

**Marilyn A. Fisher, MD, MS**

This article offers guidance on the primary ethical principles that guide medical decision-making for situations involving adults. With that background, the discussion shifts to analogous situations involving younger and older children.

### **Engaging Adolescents and Young Adults in Decision-Making** p. 31

**Suzanne S. Toce, MD**

This article builds on the previous one, covering such topics as: elements of decision-making ability; determining capacity; and engaging adolescents and young adults in decision making. The article also provides a guide to many tools and resources to help in this work.

### **Where Do We Go from Here: Advance Care Planning and Adolescents** p. 36

**Elizabeth Spellman, MSW, LSW**

This article describes the advance planning guide, *Voicing my Choices*, that was created with input from and specifically for use with adolescents and young adults. Topics covered include: where to begin; be direct; modeling; permission and acknowledgement; and be patient and reengage.

### **Supporting Sexual Health Needs of Adolescents and Young Adults (AYAs) with Chronic Illness** p. 39

**Kaitlyn M. Fladeboe, MA, Lynn Fainsilber Katz, PhD, and Abby R. Rosenberg, MD, MS, MA**

In this article, the authors “discuss the prevalence of sexual behavior and risk-taking among AYAs [adolescents and young adults] with chronic illness, review normative adolescent sexual development, and provide developmentally-informed recommendations for communicating about and supporting AYA sexual health.” Their goal is to minimize risky sexual behaviors among this population in order to avoid additional risk with negative outcomes. In addition to the main text, a table provides for parents and care providers “specific communication strategies for initiating supportive conversations, normalizing and validating experiences, providing individually-relevant information, and asking appropriate questions.”

### **Readers' Corner,** p. 44

**Suzanne S. Toce, MD**

Here, Dr. Toce provides a brief summary of a recent article from *Pediatrics* on “When Bad News Isn’t Necessarily Bad: Recognizing Provider Bias when Sharing Unexpected News.” The summary includes an abstract of the article along with comments for readers about: Who is the audience for this information? What is special about this information and where and how can I apply this information?

### **ADDITIONAL NOTES**

ChiPPS is a program of the National Hospice and Palliative Care Organization. Learn more at [www.nhpco.org/pediatrics](http://www.nhpco.org/pediatrics).

Please note that the opinions expressed by the contributors to this issue are their own and do not necessarily reflect the views of the editors of this newsletter, ChiPPS and its E-Journal Work Group, or NHPCO. We invite readers with differing points of view to submit comments or suggestions for possible publication in a future issue.

Thank you for taking time to read this issue and for any feedback that you can offer us. Providing pediatric palliative and hospice care to children, adolescents, and their family members has made great strides in recent years, even though it is certainly not always easy and still faces many challenges and obstacles. We wish you all the best in your good work. If you are not on our mailing list and received this newsletter from a friend or some other source, please send an email message to [CHIPPS2@NHPCO.org](mailto:CHIPPS2@NHPCO.org)



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requesting to be added to our mailing list. If you are a member of NHPCO, you can go to the Communications Preferences tab in your individual member record online and “opt-in” for communications from ChiPPS. Member Services will be happy to help you adjust your communications preferences; contact them at 800-646-6460. Visit the ChiPPS Web page at [www.nhpco.org/pediatrics](http://www.nhpco.org/pediatrics) for previous issues of this E-Journal, additional materials, and other resources of interest.

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## OCTOBER

Scott Newport  
 Evan's father  
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This past month I spent a bit of time with a neuroblastoma patient. One of the first things she said to me one afternoon was, "I've completed my treatment, but I'm not finished."

"Hey Brittany, lets write some poetry," I said.  
 (Over the last year we have shared our love of writing and will often read our work to one another.)

She agreed and went to hop up onto the counter in her hospital room. After her first failed attempt, Brittany turned her body allowing space to use her good leg. While she wiggled herself to get comfortable she said, "Yea, Scott, I am going through early menopause."

I gave her a nod and pulled the folding, wooden chair off its hanging space next to the hand sink and sat. I think I am the only one that ever uses the seats because they always look brand new to me. I then suggested, "I'll start out with a line and without thinking I want you to say the next line."

Below are a few of the poems that filled the pages of my notebook that special day. I picked the title, "October," because she is not an adolescent anymore. Her life is an ever-changing season. Mine too.

Winter will surely be on us soon enough.

(The bold, print lines were spoken by Brittany)  
 October  
 By N and N

Next  
 silent leaves whisper a song  
**to a tree whose leaves are gone**  
 barren voices scream for life  
**whose fate could be under a knife**

Felt  
 but today I sit by myself  
**wondering what is true health**  
 I hope it's more than greedy wealth  
**Wishing I'm heard when my knees are a kneeling- knelt**

Wondering  
 When I'm gone  
**Will there be a new dawn?**  
**Or would I have been just a pawn?**  
**Will I have finished the mission I was called upon**

Before I left, I told her if you ever want to start writing those letters to your family member's, I would help. She told me earlier, "The first one will be to my mom."

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## DEATH OF A PARENT DURING ADOLESCENCE: MY PERSONAL JOURNEY

Alexandra Hawkins  
 Jeff's daughter  
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My father, Jeff Hawkins, died from cancer on December 22, 2010. I was 14 years old. It was devastating. Although I had watched him get sicker over the course of his five-month illness, it had never occurred to me that he would die. I wasn't prepared for that possibility, although looking back, I'm not sure I could have been: How do you prepare a child for the death of a parent?

If there's anything I've learned in the near-decade since my dad's death, it's that grief is a journey. As I've grown up, my grief has grown up with me. The pain of losing my father hasn't gone away, it's just gotten easier to manage.

Grief has been a rollercoaster of emotions, with ups and downs, sharp twists, sudden drops, and the lowest of lows. I have felt sadness, guilt, and above all, anger. I am angry that this happened to me. I am angry at the world for taking my dad away from me. I am angry that his doctors could not do more to help him. A little part of me is even angry at my dad for dying. Most of all, I am angry that this is my reality. My dad did not get to see me graduate high school, and he will not see me graduate university. He wasn't there for my first heartbreak and he won't be there to walk me down the aisle or see my children. I will always be left with unanswered questions and never know what he would think about the choices that I've made in my life. I will always have regrets about my final moments with my dad, always wishing that I could have five minutes, just five more minutes, with him to tell him I love him and how much he means to me.

For the first six months, I buried my grief, focusing on school and not talking about how I was feeling. I didn't know how to deal with my feelings and it was easier to pretend that nothing had happened. People who knew would offer their condolences and I found that people usually were pretty awkward when they talked about death. I came to hate phrases like "in a better place" and "not suffering anymore," which seemed to minimize my loss. Frankly, I didn't care that my dad wasn't in pain anymore - if I could have had the choice, I would have chosen for him to be in pain, and alive, rather than dead. There were also people who made it all about themselves when offering their condolences. I had a teacher, who I liked and whose class I enjoyed, send me a disappointing email about a month after, telling me she was sorry but she "hadn't known what to say to me." I found that other teenagers and children responded better than the adults in my life; many adults, even though they knew about my loss, said tone deaf things that really hurt. I wear my dad's wedding ring on a chain around my neck. For the first few years, I got a lot of comments from people asking if I was married or saying "you're too young to have a boyfriend!" Although I'm sure it wasn't their intention, it felt like they were making fun of my loss. The worst part about people responding poorly was the fact that I still had to smile and thank them, as if they were doing me a favor by saying they were sorry. I would have preferred that people said nothing rather than saying thoughtless or hurtful things.

My first real epiphany, where the magnitude of what had happened truly hit me, was when I tried to return to camp the summer after his death. I had been at camp when my dad got sick and I associated it strongly with my memories of his illness. From the moment I got off the bus, I knew that I couldn't be there anymore. The pain was too strong, so I stayed home that summer while my mom tried to find grief support for me. To our surprise, there was little available. There were programs for children and for adults, but virtually nothing for teenagers. I tried to work through it myself by writing a 110-page novel about my dad's journey with cancer for a school project, doing research on cancer and treatments, and creating a record of his five-month illness and the time shortly after. Looking back, this was an incredibly therapeutic process and has helped me remember the last several months of my dad's life and the early days of my grief. It also allowed me to articulate how I had been feeling during that time, and it was well received by everyone who read it.



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I was able to connect with my local chapter of Bereaved Families of Ontario, where I attended a one-day workshop for grieving adolescents. While helpful, the losses of the other participants were different from mine, and I didn't feel like I connected with them. Through Bereaved Families, I was able to get involved with a program called Mentorship in Motion, where I was paired with a local artist to create a painting to promote healing through art. I also began volunteering with Bereaved Families, and I spoke at several events.

My next grief epiphany came several years later when I was in university and I joined a blog called Her Campus. I decided to write more about my experience with grief and as soon as I suggested the topic, another girl in the group reached out and shared her own experience with me. This was the first time that I had really met someone who had also lost a parent, and it helped me to realize that I am not alone. Having someone who was open and willingly talking about her experience with grief motivated me to talk more about my experiences. I have since written several articles offering tips to those who are grieving and advice for helping someone who is grieving.

Whenever I've spoken publicly about my grief, I've felt an immense amount of pressure to sugarcoat my experience, presenting it with a happy ending. I've learned that as a whole, our society is not great at dealing with grief. The death-denying nature of our society makes people uncomfortable when talking about someone who has died, and they will often try to change the subject. Grieving can feel incredibly lonely, as people tend to stop talking about the person who died shortly after the funeral. This likely stems from the fact that society tends to expect people who are grieving to "get over" the loss after some time has passed. If you aren't "over" it within that unspecified time period, then you are seen to be weak, and dwelling on the loss. In reality, the loss of my dad is not something I will ever be able to get over.

Although he is dead, my dad is still a major part of my life and there isn't a day that goes by where I don't miss and think about him. As such, it's very important to me that his memory be kept alive, and I try to speak about him often. I have found that when I do bring up my dad in conversation, people tend to become uncomfortable, even when I am sharing a happy memory or a funny story. People may think that talking to someone who is grieving about their loved one will make them sad, but I think it's one of the kindest things you can do.

My experience has taught me that good, quality support for grieving adolescents is sorely lacking. There is very little available for grieving teens, which can leave us without a support system or an outlet to talk about our grief. Although I had my mom, who was also going through the loss of my dad, her loss was completely different from mine, so she could not relate to losing a parent, just as I could not relate to losing a partner. My mom was able to find a community of other widows who supported each other through the grieving process. I didn't have that. And while my mom has been my biggest source of support throughout my journey, I would have benefitted from speaking to other young people with the same experience. I think that by encouraging grieving adolescents to seek support and having the proper resources available for them, we could reduce the stigma around grief and better support them at an already challenging time in their life. Having a place to go where I could speak openly with other adolescents who had lost a parent, would have helped me to understand that while every grief journey is different, I am not alone.

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## OUR ULTRA-MARATHON

Kathryn Cleberg  
Charlie's mother  
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On a crisp, fall day, almost 20 years ago, the ringing of our phone beckoned me to begin a journey I hesitantly set upon. A very ill baby boy named Charlie needed a family to love and care for him for what was expected to be the few remaining months of his life. My husband of 29 years and our five children started on what we anticipated would be a brief and difficult journey. That journey has turned into an ultra-marathon filled with dangerous turns, frightening obstacles, delightful and unexpected gifts, acts of amazing courage, pain, laughter, exhaustion, and countless moments that have taken my breath away.

This palliative care route with Charlie has required a variety of vital tools and equipment such as: vest machines, nebulizers with set-ups, suction equipment including tubing and yankauers, feeding pumps with feeding bags and extension tubes, formula, oxygen with masks and cannulas, a small pharmacy of medication, syringes, medicine cups, iPads, computers, splints, TLSOs, AFOs, hand splints, wheelchairs, standers, bath bench, and multiple changes of specialized clothing. Oh, and let me not forget the cases of tissues, handkerchiefs, and washcloths needed to wipe up spills, drool, and oh so many tears of pain, frustration, and joy. This myriad collection also necessitates a well running, fully accessible van and lift, ramps in our home, special hinges on the doors, cupboards, closets, drawers, shelves, and many different chargers. Oh, and don't forget the emergency generator in case of power failures. Finding and maintaining funding sources can be difficult at times and require following strict guidelines, limitation, and justifications. And heaven forbid we lose or break anything.

We have entered many varied and unexpected realms during my son's fragile and unpredictable life. These realms have fancy names like neurology: where we learned about cerebral palsy, Tourette's, perisylvian syndrome, and epilepsy. Pulmonary: to teach us about chronic lung disease, aspiration, suctioning, ventilators, pneumonia, pseudomonas infections, and chronic obstructive pulmonary disease. Gastroenterology: so Charlie's inability to swallow would not overwhelm his nutritional needs and we experienced the world of G-tubes, mic-key buttons, feeding pumps, formulas, and bowel issues. Otolaryngology: to remediate damage from cholesteatomas, remove salivary glands to decrease risk of aspiration, insert ventilation tubes, and order hearing aids to compensate for hearing loss. Plastic surgery: to lessen contractures of his hands, fingers, and arms due to arthrogryposis so we can keep him clean, relatively pain free, and fulfill his dream of having hands capable of holding the hand of the woman of his dreams. Orthopedic surgery: to place titanium rods and screws in his back to relieve restriction on his lungs and intestines caused by scoliosis. Psychiatry: to rehabilitate, enhance, and manage the broad spectrum of necessary services to improve his functional ability and quality of life. Special needs dentistry: to manage displaced teeth, thickened gums, intubation groove, and to maintain good oral health.

Throughout his life we have frequently visited many therapists specializing in occupational therapy, physical therapy, and speech therapy. We have spent countless hours in the emergency room, x-ray department, laboratory, MRI department, ultrasound department, pulmonary lab, pharmacy, pre and post op care, and pharmacies. Multiple hospitalizations have helped to maintain his life.

Last year we reached a new milestone of sorts. Charlie has 99 appointments in a little less than 12 months! And over a lifetime of 19 years he has had the experience of enduring 18 surgeries.

As we wandered, rolled, ran, and sometimes came blaring code 3 into these many seemingly mysterious realms, we have received comfort, support, guidance, reassurance, education, and care from many angels in human forms at Children's Hospital Oakland.

With each new diagnosis, I felt gob-smacked. There have been times that I felt like I was on a runaway train or a gigantic roller coaster complete with hair raising dips and death defying loops and turns. Deep



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breathing, pausing, prayer, clinging to hope, and a belief in my ability to learn whatever was necessary to care for this precious son gave me the stamina to carry on no matter how overwhelmed, exhausted, or frightened I felt. I discovered that relinquishing myself to fully experience each situation we found ourselves in worked far better than resisting situations I had little or no control over. A book authored by Nina Lesowitz and Mary Beth Sammons, *The Courage Companion, How to Live Life with True Power* has been very helpful to me. My favorite quote is “Courage can be a form of tenaciousness, a refusal to quit because you are tired, hurt, humiliate, or emotionally broken. Courage it’s the ability to face what life throws in your path on a daily basis.”

During our journey we have been blessed with sherpas of various kinds. People walk beside us and lessen the load we carry. They consist of members of our church community and neighborhood. Our service dog, Flori, was provided free of charge to us by Canine Companions for Independence in Santa Rosa. A home nursing agency provided us our wonderful nurse, Shirley, five days a week for five hours a day. Our older children, their spouses, and our grandchildren have been our constant companions.

About 13 years ago we stumbled upon an amazing pediatric palliative care facility known as George Mark Children’s House in San Leandro. We were referred to “the house” by a hospital chaplain, Sr. Bernice, during one of Charlie’s many stays in the pediatric intensive care unit. The respite care that Charlie and our family receive there has greatly improved the quality of our lives. They serve as Charlie’s “home away from home” and provide all of us comfort, care, joy, and encouragement.

Our experience as travelers on these many paths, roads, trails, and wilderness has built an intense sense of intimacy between my son and me. I care for his most personal needs. Together we have experienced highs and lows, fear and hesitation, loss and grief, joy and laughter, exhilaration and euphoria. We trust one another and have faith in each of our individual abilities and limitations to carry us through day by day.

Over the 19 years of Charlie’s life, as we look back at where we’ve been, we have a sense of pride and accomplishment. I think we’ve done a good job of meeting his physical, spiritual, educational, emotional, and social needs. Charlie exudes grit. He is confident, cheerful, has a great sense of humor, and always sees the sunny side of life. He loves music, Legos, train travel, hot cars, video games, women, friends, and family. He enjoys playing power soccer with Bay Area Outreach and Recreation Program (BORG) in Berkeley, Ca. Several times a year he runs/rolls in foot races, including Bay to Breakers, with his father and older brother. If you asked him to tell you about a bad day, he would deny ever having one because he truly believes that every day is a good day. His motto is “Love Life.” His favorite color is orange. He works four hours a day, four days a week as a groundskeeper at our local community college and donates most of his wages to George Mark house and our church. He has learned to enjoy life in spite of having upper limb paralysis and is competent at accessing his environment with his feet.



As this journey continues, I do not know where the path we walk will lead. I sometimes fear storms on the horizon. Who will care for him when his father and I are no longer physically or mentally capable of continuing to provide the intensive level of care he requires? What will happen to the quality of his life after he transitions into the world of adult medical care and loses many resources that have bolstered him and us for so many years? Will other caregivers keep him clean, trim his mustache, respect his wishes, and help him stay engaged with his community? Will he continue to experience joy, love, and hope? Will he remain gritty and continue to love his life?





Our ultra-marathon has always lacked one person that I believe could have lessened the degree of turmoil and confusion we experience as we maneuvered our way around obstacles and challenges. The presence of a tour guide (case manager) would have been wonderful. That vital guide could have alerted us to possible difficulties, pointed us toward resources, highlighted alternative routes, and helped us cope with new situation as they rose before us.

As Charlie enters his 20's and I my 70's we will courageously move forward, confronting a future of unknowns. My prayer is that someone will be there to help us maneuver our way around new hills and through deep valleys until my son and I breathe our last breaths and are free from the challenges of life. In the meantime, I find strength and hope in the words of Mary Anne Radmacher.... "Courage doesn't always roar. Sometimes courage is the little voice at the end of the day that says I'll try again tomorrow."

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## DOUGLAS HOUSE, A “RESPICE” FOR YOUNG ADULTS

Sister Frances Dominica  
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### Sister Frances Dominica writes:

In 1982 Helen House, the world's first children's hospice, opened in Oxford, England. It grew out of my friendship with the family of a two-year-old child. Helen had suffered catastrophic brain damage as a result of an intractable cerebral tumor. I am a registered pediatric nurse and a sister in an Anglican religious community. Helen's parents trusted me to care for Helen occasionally, so enabling them to catch up on sleep after repeated broken nights, to focus on the other children in the family, to have a short holiday or, on occasion, to have Helen to stay when they themselves were unwell or exhausted. In due course, in partnership with Helen's parents, we decided to extend our friendship and practical help to other families with a child or children with life-shortening conditions.

When Helen House opened we did not know who would use it – if anyone. Pediatricians were slow to refer, but gradually word spread from family to family. The outside world assumed that the word “hospice” spelt cancer but with children it proved to be different. The majority of children who came to us had slowly progressive, life-shortening conditions such as Duchenne muscular dystrophy, spinal muscular atrophy, cystic fibrosis, Batten's disease, and a number of the various mucopolysaccharidoses. In 1982 life expectancy was relatively short for these children and it seemed reasonable to set our upper age limit for new referrals at 16, but as time went by advances in treatment meant that many were living much longer than they might previously have done.

In 2002, twenty years after Helen House opened, we found that 23 of our “children” were now over 20, one being 27 years old, 1.8 meters tall and hyperactive! It was clearly time to do something.

We appointed architects who asked to meet with some of our young friends to find out from them what they wanted in the new building. We had a barbeque, and, after appropriate amounts of alcohol, suggestions flowed:

- Larger bedrooms so they could socialize in their electric wheelchairs
- A long wide corridor so they could race in their chairs
- A music room with thick walls so no one would complain about the noise when they were jamming. (They got that but rarely shut the door...)
- A parent-free zone
- A bar with free drinks so they could relax in the evenings
- Anything and everything to give them independence

They got all they asked for and when we invited them to tour the new building all they could say was “Wow!” Then one of them said, “This isn't a hospice, it's more like a good hotel!” From then on those who came to stay in Douglas House were not called patients but guests.

Her Majesty the Queen graciously opened the house, accompanied by His Royal Highness the Duke of Edinburgh.

As with Helen House we offered respite care, symptom control, stepped discharge from hospital, end-of-life care, and long-term family support. Fundamentally, it was an attempt to encourage and enable these young people between the ages of 16 and 35 to live life to the full, however long or short that life might be.



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### Chris Bloor writes out of his experience working on the Douglas House care team:

I worked as a registered nurse at Douglas House for over 9 years from 2004.

The main aim or ethos of the developing care team was to provide an environment which was not over-protective and “motherly” as it needed to be in Helen House, the children’s hospice, but a caring space which would allow young life-limited people to have a break from their day-to-day life at home. They needed a place where they would be able to meet friends and peers, knowing that they could spend as much time as they liked chewing the fat into the wee small hours.

The “guests”, as they were called, needed a **non-judgmental environment** – a very glib comment, which is often very hard to achieve in a care setting. The staff at Douglas House did their best to enable it and, on most occasions, managed to do so. The young people wanted as much **independence** as possible, something that most people of their age take for granted; however it is not often possible for those who have severe disabilities associated with a life-limiting condition to achieve it.

On many occasions the staff at Douglas House supported young people to **express their individuality** on a variety of levels. However, as with any one else of that age, the consequences were often all too evident. Many hangovers and bleary eyes could testify to this, as could the numerous paint splashes on the art room floor and the complaints from the neighbors about the noise from a jamming session. We tried to provide a **safe environment** in which the guests were able to take **risks**, just as all young people need to do as part of growing into adulthood. The risks included camping in a tent at the Glastonbury Music Festival or taking a chance on a relationship. **Trust** needed to be built between the guest and the care team, with the understanding that it was a two-way contract, always recognizing the results of breaking that trust. We got this right a lot of the time but disastrously wrong on occasion.

**Friendship** is something that is hardly ever encouraged and rarely spoken about in the general care setting. Members of the Douglas House team were encouraged to have a relationship based on friendship rather than the more conventional patient /professional relationship. This was I feel, and still is, one of the hardest concepts for nurses, doctors and carers to understand.

Finally, we did our best to reassure the guests that, when the time came to die, here was a place where we would do everything we could to make the end as comfortable, dignified, and safe as possible and that we would continue to support their families for as long as they might wish.

### Matthew O’Sullivan describes his experience as a guest:

I have received respite care at Douglas House from 2006. During my visits I’ve experienced eye-opening, funny, happy, and sad times.

When I was first introduced to the idea of a hospice I wasn’t entirely convinced. I had many preconceptions of a “hospice” environment being very hospitalized, solely based on health needs of patients instead of their overall wellbeing. Having quite a positive outlook on life and my medical condition, Duchenne Muscular Dystrophy, I had always considered myself a ‘glass half full’ person but I feared that going into a hospice would lead me to become institutionalized.

After chatting to a few members of the Douglas House team I was convinced to go to an open day. To say that my preconceptions were wrong would be an understatement. I was amazed by the comfortable, laid back nature of the surroundings, giving the atmosphere of a 5-star hotel rather than the hospice I had imagined. From the free bar to the Jacuzzi room, to the bedrooms, each section had its own wow factor.

During the many years I stayed at Douglas House I had some fascinating experiences I never thought would have been possible. These included camping at WOMAD festival, visiting Silverstone Race Track, and meeting celebrities. But without doubt the biggest and most enjoyable experience has to be the ten-day trip to Japan. It was not only a once-in-a-lifetime opportunity, it was also the first time I had been



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abroad without my family which wouldn't have been possible without the dedication and support of the staff.

The social aspect was a big factor in the enjoyment of staying at Douglas House. I've made many long-term friends through nights in at the bar, days out, and everything in-between, both with other guests and staff. I think that the way the hospice works in terms of trust between other guests and staff members is part of the reason it was so successful, becoming a benchmark in hospice care.

Later in my time at the hospice I began to bring my long-term partner with me, so we could both get respite from managing carers. This was accepted without an issue, even small things such as sleeping in the same room and being able to have time alone, knowing help wasn't far away.

Not only have Douglas House staff been there for the good times, they are also there through the bad times with the guests and their families. Whether it's the medical condition getting too much, or the death of a close friend made at the hospice, the team are there at any time for support. The onsite psychologist and also all the care and nursing staff have got me through some bad times over the years.

To say Douglas House is just a hospice would not be doing it justice. It is much more than that - it's a family, a support network, a place for dreams to become a reality, and a perfect insight into the ethos all hospices should adopt.

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## WHAT WE'VE LEARNED ABOUT ADOLESCENTS AND YOUNG ADULTS WHO ARE GRIEVING

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*"Siri, when do I have time to grieve?"*

The stories shared are heartbreaking. Each one is unique. They're complicated and comprised of pain, confusion, introspection, and hope – and so much more. Many adolescents and young adults struggle to find a way to manage what they are experiencing on their grief journey. Do they recognize the importance of taking care of their grieving needs? Do they know where they can go for support?

As a member of the clinical team working at Highmark Caring Place, a center for grieving children, adolescents, and their families, I've companioned many grieving teens and more recently, young adults. I've had the privilege to serve as a caring, trusted adult in their lives; to listen as they share about their loved ones, to help them process, and to offer support. The work we do in offering peer support is largely therapeutic to the grieving children and teens who participate in our program. But after teens age out of our program by graduating from high school, we've found that there is often not a good fit for them to continue participating in our groups. They often can't relate any longer to the teens (13-18) nor can they relate to the grieving experiences of the adults who are their parents/caregivers age or older. Recognizing this, a clinical consideration for us then became how do we best serve the needs of this 18-30 age group?

After doing considerable research into grief support groups being offered across the nation and speaking with leaders in the field of thanatology about what is working and what's not, I came to the conclusion that these young adults can easily fall into the "forgotten or overlooked grievers" category. Further, I found that support services are rarely available or offered to this age group – even on college campuses! Young adults are driven to seek out individual counseling if they desire support as it's often their only option.

In 2016, we decided to take this issue on and run a pilot young adult grief support group. The response we received from the professionals in our community was positive and affirmed that there was a need and made referrals. Parents/caregivers responded on behalf of their young adults. Young adults themselves though rarely reached out for support. Hence, that was one of the key findings from offering this pilot – engagement is a big challenge with this age group. They report that they're busy! Whether they're busy because of societal expectations and the perceived natural progression of young adulthood (e.g., school/college, graduation, get a job, get an apartment or buy a house, get married, have kids, etc.) or as a means of coping in response to the death, the majority don't have time to dedicate for a support group. Or, they don't recognize the importance of making the time until their health and wellness is impacted. Our young adults tell us they often don't realize they have unresolved grief until it overwhelms them when they have down time during those young adult life transitions.

The boxes on the following pages illustrate some of what's been shared with us about young adult grief. During group time we talk about the death, their feelings, memories, what changes and challenges they've experienced after the death, as well as strategies for coping.



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**Feelings:**

*Isolated      Resilient      Anger      Burdened      Restless*  
*Envy      Strong      Raw      Disbelief*  
*Numbness      Guilty      'Set-back'      Deep pain      Need to cry*  
*'On a rollercoaster'      More absentminded-can't concentrate*  
*'Don't know what to do'      Bitterness      Depressed*  
*'Stuck back in the day when I found out'      Frustrated*  
*Empty      Heartbroken      Anxious      Sad*  
*Overwhelmed      Nostalgic      Introspective*

**Changes:**

*Everything has changed!*  
*Joy is missing ...*  
*Now any life change is different*  
*A big piece of me is missing*  
*More compassion for those really suffering*  
*Less tolerant of those who aren't being authentic*  
*New perspective of what it means to 'support'*  
*New triggers*  
*Chasing of my dreams is on hold*  
*Hard to compartmentalize; hard to process*  
*Inventory of friendships ... have seen 'true colors'*  
*See all differently, like all is filtered, like a veil*  
*Lots of emotions around transitions*  
*Loss of direction*  
*Relationships...*  
*It's hard to enjoy ...*

**Coping:**

*Writing/journaling*  
*Video blogging*  
*Isolating – stay in my room*  
*Going to 'watch the trains' – a loved one's favorite thing*  
*Cry – by myself*  
*Pets*  
*Listen/play music*  
*Private blog*  
*Try different hobbies*  
*Work*  
*Help out with youth group at church – try to find purpose*  
*Camping*

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**Challenges:**

*More responsibility at home*  
*Where do I fit in now?*  
*Balancing home needs with my needs*  
*How to stay connected with my family?*  
*Comforting others when I need comfort too*  
*How to be an adult*  
*Holidays*  
*Worrying about those you love*  
*Protective of my feelings*  
*Protective of my parents' feelings*  
*Not sharing my own grief with family members*  
*Acting stronger than I am*  
*Feeling obligated*  
*Managing emotional closeness (wanted and unwanted)*  
*Don't know where to get comfort from*  
*Don't want to draw attention, but need support*  
*Survivor's guilt*  
*Opportunities lost*  
*Fear of losing memories*  
*Others being afraid to ask or talk about the death*  
*Asking 'why'? What is the meaning of what's happened?*

To summarize: there are a multitude of emotions tied to the losses they've experienced; the changes and challenges facing them are real – and very difficult to manage; and our young adults are often hesitant to ask for or accept support as they try to find ways of coping with the death.

The italicized sentence at the head of this article is, I believe, a true representation of how our grieving young adults try to manage the challenge of taking care of grieving needs with their busy lifestyles. Whether they are personally driven or following societal expectations, they have so much to accomplish and so little time. How does one offer support? How do we meet this age group where they are?

We, at Highmark Caring Place, strive to raise awareness and give a voice to the unique needs of this population by continuing to explore ways to meet their needs. By continuing to offer young adult grief support groups a couple of times a year, presenting on this topic, and partnering with local colleges/universities to explore ways of reaching this age group (i.e., using technology to pilot virtual groups), we hope to find ways to bridge the gap in supports for this age group. We're accepting the fact that a complicating factor in reaching this audience may be the influence of the digital world and how this group is connecting today.

It is our hope that you will help “bridge a gap” when you have the opportunity to support a grieving young adult in the important work you are doing. Be courageous and start the conversation by asking, “How are you doing today?” or “Tell me about (name of deceased).” Just by asking the question, you show you are


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willing to listen and that you are OK with what may be shared. You will be a trusting, caring adult companioning a young adult on their grief journey.

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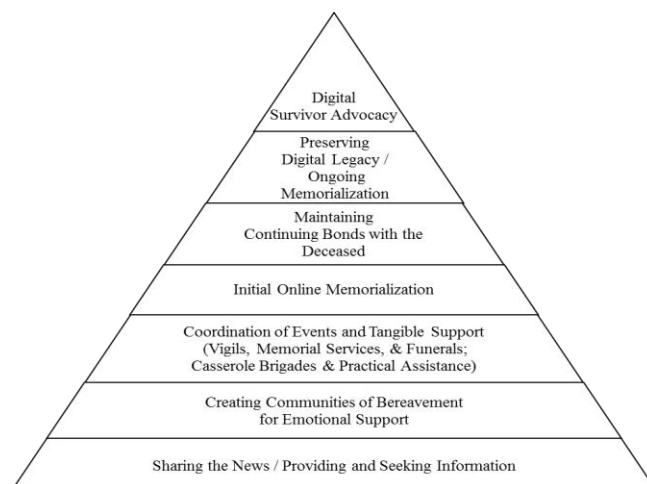


## ADOLESCENTS' USE OF SOCIAL MEDIA AND DIGITAL TECHNOLOGY TO COPE WITH LIFE-THREATENING ILLNESS AND LOSS: WHAT PARENTS AND SUPPORTIVE ADULTS SHOULD KNOW

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Most teenagers use social media and technology on a daily basis, with 91% using text messaging tools (NORC Center for Public Affairs Research, 2017) and 94% going online each day using a mobile device (Lenhart, 2015). When adolescents experience life-threatening illness, grief, or tragedy, they are using thanatechnology—digital technology and social media (Sofka, 1997; Sofka, Cupit, & Gilbert, 2012)—to cope with these adverse life events.

A growing body of literature has documented multiple uses for digital and social media during times of illness and loss that are summarized in this pyramid. Regardless of one's role in a teen's life (professional helper, parent, or supportive adult), it is important to be knowledgeable about the ways that teens are using thanatechnology and to consider how you can assist young adults in making wise decisions about using these resources.



Source: Updated version of figure from Sofka (2015)

### Death Notification: Think Before You Post

Do teens have a preference for sharing bad news face to face or through the use of thanatechnology? Since the leading causes of adolescent death are often sudden (Cupit & Meyer, 2014), parents or adults in authoritative roles (e.g., school officials, teachers, helping professionals) may have little to no control over how teens are informed about the death of a peer. Current “netiquette” allows the use of social networking sites (SNS) and social media as appropriate mechanisms to share information about a death or a tragedy, and “bad news” travels fast.

According to a survey of people who used digital and social media to cope with the deaths of two teenagers (Chris and Deanna) involved in a car crash (referred to as the “518” case due to the area code), 61% learned about the car crash within the first hour after it occurred at 10:17 PM on a Saturday night (Sofka, 2018). Almost one-third of the respondents who were high school students found out about the crash on Twitter (e.g., #ripchrisanddeanna), with almost 12% getting the news on Facebook (FB) and 3.3% through Instagram. Text messaging also played a significant role, with 17% learning about the crash in this way.

When asked about preferences for receiving “bad news,” comments reflected a wide range:

Face to face: “I was glad that I received the news in person. It decreased the shock of seeing the news over social media.”

Technology-mediated notification: “As someone who is not completely comfortable showing strong emotions in front of people, I am okay with receiving the news over text.”



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Some students reported distress due to not knowing the identity of the victims or as a result of receiving misinformation about who had died or survived. One victim's mother described the urgency of reaching her college-aged son to prevent him from learning of his brother's death on social media. It is difficult to anticipate all the potential consequences of prematurely sharing information about a tragedy on social media.

### **Gaining Emotional and Informational Support**

Once teens learn that a death has occurred, they sometimes turn to SNS to seek emotional support from their existing online communities or ones that evolve through the creation of memorial/RIP pages (Irwin, 2015; James, 2014; Kasket, 2012; Sofka, 2018; Williams & Merten, 2009). Connecting with others experiencing similar losses combined with the opportunity to receive instant feedback and support can be helpful (James 2014), and research has documented that teens take comfort in providing support to their peers and the deceased's family.

In addition to being able to "normalize" their experiences, teens can gain information about an illness or how to cope with grief from organizations such as the Dougy Center, the Open to Hope Foundation, and GriefNet. The Teen Health and Wellness website contains information about physical and mental health topics as well as contact information for hotlines that provide bereavement support. However, adults should help adolescents to gain "information literacy" skills to evaluate the reliability of online sources (see Sofka, 2012).

Twitter is also used to share personal reactions to loss or to provide support for peers who are grieving. Within 72 hours of the "518 case" crash, teens from local high schools (sports rivals) sent supportive messages (using hashtags #518Strong or #518Family), such as "the best kind of rivalry is one where it goes away when something horrible becomes bigger than the rivalry ever could be." The survivors' friends started Twitter campaigns that encouraged the survivors' favorite athletes to call them in the hospital (#MissyCallBailey and #TebowCallMatt), and both survivors received a call. One survivor, already a prolific tweeter, shared her grief journey on Twitter (see Wind, 2013). Tweeting may be popular among public grieverers who prefer quick and easy-to-use technology.

Depending on the privacy settings used for SNS, comments from complete strangers may appear on the SNS of deceased adolescents. DeGroot (2014) coined the term "emotional rubberneckerers" to describe "online voyeurs who visit the FB memorials of strangers or distant acquaintances to read what others write and to post their own messages of grief" (p. 79) and noted that "although the term rubbernecking has a negative connotation, emotional rubberneckerers are not always seen as negative elements" (p.82).

Since many of these strangers can relate to the situation in some way (identifying with the deceased's age, cause of death, etc.), I would like to propose use of the term "experiential empathy" to capture the social media user's motive for becoming involved due to his or her ability to relate to the other grieverers based on a similar loss experience. For example, one "518" respondent who did not know anyone involved in the crash participated in social media because he could relate strongly to the current circumstances: "I was at a high school when my cousin passed away in an accident." Sadly, grieving the death of a stranger in cyberspace may be more socially acceptable than it is to express one's deep and heartfelt grief for a loved one in the real world, where many people don't know how to provide social support to grieving teens. In addition to alleviating feelings of loneliness and isolation, teens feel supported by the postings of strangers (James, 2014).

### **Resources for Memorialization and Creative Expression of Grief**

Almost immediately after a young adult's death, SNS become outlets for the expression of grief and the preservation of the deceased's digital legacy begins. Postings include the sharing of memories and descriptions of relationships with the deceased (James, 2014; Williams & Merten, 2009). Teens use photos to remember the person's physical image, including social media previously shared by the



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deceased (James, 2014). One teen in the “518 case” posted video footage of her deceased friend because “It’s just so nice to hear his voice.”

When asked about the origin of the FB memorial page in the “518 case” for one of the deceased teenagers, his mother noted that it was created by her son’s friend who eventually transferred administrative responsibilities to her. Facebook allows the designation of a “legacy contact” who is given privileges to manage the page following the owner’s death. The option to “memorialize” a page is still available in the event that a FB user dies without implementing this option, but this option prevents new postings from being made on the page.

Social media and SNS provide opportunities for teens to express their true feelings about loss by sharing visual media and postings with a sense of perceived safety that they may not find in face-to-face conversations (James, 2014). Thimm and Nehls (2017) describe the uploading of photos on Instagram as an everyday ritual performed to obtain support from online communities and found examples of digital storytelling that facilitate the expression of emotions as well as interacting with others who can relate to their loss. Storify and YouTube can be used to create memorial tributes to the deceased, which are often viewed by fellow grievers.

General blogging sites such as LiveJournal or WordPress can be used by teens to write about their grief. In addition to providing a forum for sharing stories, the KidSaid.com component of GriefNet facilitates the sharing of artwork. If listening to music and “playlisting grief” is a preferred strategy for coping with loss, teens can create and share their playlists on SNS and social media (Sofka, 2014).

### **Continuing Bonds with the Deceased**

In an early study of postings on SNS by grieving teens, Williams and Merten (2009) noted direct messages to the deceased (e.g., “We will miss you” or “I love you”). Content included reminiscing with the deceased about prior shared experiences, providing updates about current events, or sending messages on significant dates (e.g., birthdays, holidays, major life events where the deceased’s presence is missed, or the anniversary of the death). Data from the “518” case (Sofka, 2017a) confirms that young adults continue to post and tweet in honor of their friends over time (“Three years later and things never get easier, miss you both more every day. Keep watching over us”). These communications demonstrate a “continuing bond” (Klass, Silverman, & Nickman, 1996) that allows teens to maintain a technology-mediated connection with their friend or loved one through the use of social media, reflecting the belief that the deceased is receiving these messages (Kasket, 2012).

In addition to confirming Williams and Merten’s findings, recent studies of this phenomenon describe additional aspects of direct messages to the deceased (Irwin, 2015; James, 2014; Kasket, 2012; Sofka, 2017a). Private messaging functions on social media provide teens with a non-public forum to say “I’m sorry” in cases where friends were unable to resolve a disagreement or to take care of any “unfinished business” prior to the death. Williams and Merten (2009) also reported comments from peripheral friends (those on the outer circle of the deceased’s social network) that reflect regret at not having known someone better (e.g., “I wish I would have taken [sic] you up on those ‘wanna hang out?’s” p. 83).

Some teens may post messages to the deceased to let him or her know that (s)he is loved or that someone is praying for him/her and their family (James, 2014). As a result of these messages, one respondent imagined that their friend could experience happiness and comfort. Facebook can also be used to update the deceased on everyday occurrences (Kasket, 2012). Some postings make requests for the deceased to watch over them from the afterlife or express the hope of being reunited in the future (Irwin, 2015).

While many teens clearly know that they will not receive a direct response to their messages, others may hope for a response through dreams or other phenomena (James, 2014; Kasket, 2012), described by Irwin (2015) as a “paranormal co-presence” or after-death communication. Following the sudden death of his friend, one teen in the “518 case” stated: “In some ways I felt like they were going to respond.”



Because at that point, it was all still a dream” (Sofka, 2017a). Once the initial shock of an unanticipated loss dissipates, this expectation may disappear.

### Funeral Selfies

While conducting interviews with students about the role of social media in their lives, Freitas (2017) met one college senior who speculated that in 50 years, her generation would be dubbed “the Selfie Generation.” Many described selfies as tools for documenting and remembering experiences. Since many of the interviewees noted that photos and postings on social media should be happy and positive (which Freitas named “the happiness effect”), it is fascinating to consider the presence of “funeral selfies”.

Teenagers are posting selfies on Instagram, Tumblr, Twitter, and other social networking sites that capture images related to the death of a significant other (for examples, see Feifer, 2013, & Wabash n.d.). During the Victorian era, post-mortem photographs were often taken of infants and children due to high mortality rates combined with the prohibitive cost of photographs (Christian, 2016). However, during a time when teenagers constantly post photos on social media, what motivates some young adults to capture and share images related to the death of a significant other?

The practice of taking funeral selfies is controversial (Cupit & Kuchta, 2017). Discussions and debates about why this practice occurs and if it is appropriate can be found in a variety of sources ranging from newspapers and blogs (Allan, 2018; Boulton, 2017; Feifer, 2013; Moye, 2015; Wabash, n.d.; Wilde 2014) to YouTube videos on etiquette (*Wall Street Journal*, 2013) to academic publications (Cupit & Kuchta, 2017; Gibbs, Meese, Arnold, Nansen, & Carter, 2015; Thimm & Nehls, 2017).

Studies analyzing images with the hashtag #funeral (Gibbs et al., 2015; Thimm & Nehls, 2017) have noted that most selfies include only the user, group selfies with family and friends, and funeral-related objects (candles, flowers, memorial cards, gravestones, etc.); only a small percentage show the deceased. Pets as objects of grief were also represented along with memes and popular culture references. While some of the selfies seem to be about self-promotion (#fashion - dressed in funeral attire) and contribute to interpretations of this practice as narcissistic, others reflect the sharing of one’s experiences (#SadDay). Some comments combine the two (“Love my hair today, hate why I’m dressed up” – Drimonis, 2017). A video posted by Whistle Blower (2017) includes selfies with the deceased.

Cupit and Kuchta (2017) speculate that funeral selfies either affirm one’s presence at a funeral (although this is viewed as disrespectful by their elders), serve as a token of love/remembrance, or create pictorial narratives that inform a person’s online social network about a death. According to Gibbs and colleagues. (2015), these photo-sharing practices indicate a changing relationship between death and photography. Individual selfies visually communicate a person’s presence in relation to the funeral to one’s wider social network, creating a sense of proximity or connection with those who cannot be present. Group selfies are often taken immediately after the funeral and celebrate the sense of community that is created following a death. Sadly, a funeral may be one of the few times that extended families are together.

Funeral directors and others do not agree on the appropriateness of funeral selfies. Some are concerned that the family of the deceased will not want reminders of their loss, and that selfies are generally in poor taste (Allan, 2018; Boulton, 2017). Palliative care physician Mark Taubert believes that funeral selfies divert attention away from the deceased (Fussell, 2016).

On the other hand, Feifer (2013) believes that teens use selfies to express emotions for which they may not have words, using visual language that adults simply don’t speak. Funeral director Wilde (2014) describes emerging culture as caring more about belonging than decorum, and notes that funeral selfies are often about informing others that “part of my community has died, and I just wanted to let you know” (para. 10/11). Thimm and Nehls (2017) note that some postings describe the loss of a loved one by using creative visual and textual storytelling techniques, which then engage the digital public in a supportive manner.





## Digital Survivor Advocacy

Some people who survive a traumatic loss channel their grief into preventive action (Trauma Foundation, 2001). These "survivor advocates" hope to save others from experiencing a similar loss and trauma through efforts that educate, raise awareness, and change policy. Although digital survivor advocacy efforts are relatively unexplored (Sofka, 2017b), student survivors of the mass shooting at Marjory Stoneman Douglas High School (MSD) in Parkland, Florida, on February 14, 2018, put this strategy for coping with grief in the national headlines.

In addition to participating in survivor advocacy efforts via traditional news media, conducting town hall meetings, and visiting elected officials, students from MSD engaged in digital survivor advocacy efforts using social media. Twitter hashtags such as #NeverAgain, #MSDPickUpAPen, and WeCallBS were used in advocacy efforts such as letter writing campaigns to politicians to prevent gun violence. MSD students also promoted a #MarchForOurLives on March 24, 2018, with the goal of pushing Congress to pass legislation that would make schools safer and prevent future deaths (#DontLetMyFriendsDie).

When people experience a tragedy, what motivates them to participate in survivor advocacy efforts? Only days after the shooting, survivor Emma Gonzalez (@Emma4Change) eloquently stated:

"Every single person up here today...should be home grieving. But instead we are up here standing together because if all our government and President can do is send thoughts and prayers, then it's time for victims to be the change that we need to see" (CNN Staff, 2018).

MSD students were criticized by some for raising their voices, suggesting that they take time to grieve instead. In her comments to reporters, Ms. Gonzalez educated her critics about how her grief and her advocacy efforts were connected:

"Everybody needs to know how we feel and what we went through, because if they don't, they're not going to be able to understand why we're fighting for what we're fighting for...This is the way I have to grieve." (Turkewitz, Stevens, & Bailey, 2018).

Shooting survivor Cameron Kasky described his desire to **team** up with classmates to promote a movement against gun violence to Smidt (2018) in the following way: "We, as a community, needed one thing" - a purpose amid their grief. While anecdotal evidence suggests that these and other survivor advocacy efforts help the bereaved to cope with their grief (Sofka, 2017b), it will be important to learn from those who participate in these initiatives about whether involvement facilitates and/or hinders the process of coping with loss.

## Suggestions for Parents and Supportive Adults

- 1) Smartphones and social media will undoubtedly have a role in sharing news about tragedies. Teens and their parents should be encouraged to discuss the pros and cons of sharing this type of information via technology (see Box 1&2), as well as the impact that premature sharing of a death may have on a close relative or friend who deserves to find out in a more personal manner. Conversations prior to a crisis will facilitate everyone's ability to make informed decisions about how to proceed when faced with a tragedy.





### Box 1: Benefits of Digital and Social Media Use

#### Benefits:

- Notification of a death: Factual information can be sent quickly to multiple recipients (can reduce the burden of making numerous phone calls or sending multiple messages) provided that the intended recipients see the information.
- Links to online information can be shared easily (e.g., online obituary, information about funeral services or memorial events, online guestbook, fundraising sites, coordinating a “casserole brigade” at [www.mealtrain.com](http://www.mealtrain.com)).
- Memorial (RIP) Pages / Blogging / Microblogging:
  - Provides a 24/7 outlet for the expression of thoughts and feelings through the sharing of photos and memories.
  - Memorial pages creates a “social support internetnetwork”; visitors can express condolences and post messages of support.
  - Postings can educate social media users about grief; comments can validate a person’s experiences.
- Participation in Digital Survivor Advocacy: May facilitate coping with grief as a result of advocating for change after a tragedy (something positive comes from a negative life event)

### Box 2: Risks and Challenges of Digital and Social Media Use

#### Risks / Challenges:

- Notification of a death:
  - Some people may prefer to receive “bad news” in a more personal way (face to face or a phone call) or under different circumstances (in a public vs. private place when receiving the news; being alone vs. with someone to provide support).
  - Inaccurate information can be shared prematurely, particularly in the case of a sudden/accidental death.
  - Once the information is shared publically, no one can control how and with whom the information is ultimately shared.
- Anyone can post anything online; digital/social media users must carefully evaluate the reliability of information.
- Memorial (RIP) Pages / Blogging / Microblogging:
  - Administrator(s) of sites need(s) to monitor postings, remove inappropriate comments, and/or block trolls.
  - Users may experience distress in reaction to photos or content that is unanticipated, upsetting, or unwanted.
  - Users may experience cyberbullying or criticism for publically sharing one’s personal experiences.
  - Public postings online may contribute to a loss of privacy in “real life”.
  - Users may experience a dilemma about the decision to stop blogging / posting (feeling responsible for “followers”).
- Digital Survivor Advocacy:
  - Desired changes in awareness, attitudes, behaviors, or policies/legislation may occur very slowly or not at all.
  - The bereaved may be criticized by those who do not understand that survivor advocacy is an appropriate strategy for dealing with grief, particularly if one begins advocacy efforts very quickly after the loss.



- 2) Since unanticipated death can be a reality for families with teenagers, parents should gain information about planning for one's "digital legacy" (see Sofka, Gibson, & Silberman, 2017c; <https://digitallegacyassociation.org/social-media-will-template/>) and learn about options for managing social media accounts in the event of a death and discuss them with their children once they are old enough to use social media (see Shavit, 2015 for user-friendly resources). Helping professionals, particularly those who interact with teens and families experiencing a life-threatening illness or sudden loss, should facilitate conversations about these options and help patients and families to prepare digital advance directives.
- 3) Family members and clinicians who interact with grieving teens should engage in conversations about their use of digital and social media resources to cope with grief as well as the impact of their use on their grief journey (see Box 3).
- 4) The controversy about funeral selfies is likely to continue. Parents should discuss the appropriateness of funeral selfies (or the taking of any photos of the deceased) with their teens and gain permission from the deceased's immediate family before taking any photos of the deceased and/or publicly posting them on social media.
- 5) Help survivors of tragedy to determine if and when they are ready to participate in digital survivor advocacy efforts and the potential benefits and challenges/risks. Parents and helping professionals should provide guidance and support as teens navigate the complex legal, legislative, and social systems involved in policy change as well as the potentially politically-charged situations that contribute to tragedy.
- 6) Parents and helping professionals have a responsibility to educate adolescents about the risks associated with digital and social media use. These risks include cyberbullying/cyber-suicide, memorial trolling, and Facebook depression (Alvarez, Speere, & Blinder, 2013; Cupit & Kuchta, 2017; Hinduja & Patchin, 2010; Smith & Cavuoti, 2014; Sofka, 2018; Thimm & Nehls, 2017).
- 7) Opportunities for "netiquette lessons" and education about the wise use of thanatechnology must be provided for teens, their parents, and professionals who work with them (James, 2014; Sofka, 2017a). Consider creative partnerships between helping professionals in hospice, schools, community mental health agencies, and other mechanisms for community education such as PTA workshops, public libraries, and community adult education programs.
- 8) Guidance should be provided to schools and other organizations that serve adolescents to help them create effective social and digital media policies that respect the role of technology in teenagers' lives (Frost, 2014; Sofka, 2017a).

## Conclusions

Participation on SNS and social media can help adolescents to cope with life-threatening illness and loss. As James (2014) noted, Facebook use helps to "unify" people and perhaps collectively overcome their grief. Although we have learned a great deal about the benefits of social and digital media use during times of tragedy and loss, there are also risks and challenges. However, there is a great deal more for us to learn, including how to measure the impact of digital technology use on the social and emotional well-being of bereaved adolescents.

We would be wise to remember that today's teenagers are what Freitas (2017) called "pioneers of a virtual world," describing them as brave and courageous "new explorers" (p. 251). I encourage readers to invite the teens in your life to be partners in our efforts to understand the best way to maximize the benefits and minimize the risks of coping with loss in the digital world.



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**Box 3: Assessing the Use of Thanatechnology / Social Media and Digital Social Support (Social Support “Internetworks”)**

**Question #1:** Have you ever used technology or social media in any way to deal any aspect of coping with illness, dying/death, and or grief? \_\_\_\_ No \_\_\_\_ Yes: If so, please place a check in front of each resource that you have used.

Facebook: ____ Individual page(s) ____ Other (describe): MySpace ____ RIP page(s)		Memorial website(s) other than FB/MySpace (describe):	
Online discussion group/chat group/support group (describe):			
Online obituary: ____ I read it ____ I shared the link (where?)		Online guestbook: ____ Read the entries ____ Added an entry	
Twitter	Tumblr	Pinterest	Instagram
Text messaging (TM)	Instant messaging (IM)	Flickr	Spotify
Skype / WhatsApp	Snapchat	WeGram	Kik
YouTube (for non-music videos):		YouTube, Pandora, Vevo, etc. (access to music):	
MP3 player / iPod - Describe playlist(s) related to grief/loss:			
Other (describe):			

**Question #2:** Have you ever learned about a death or a tragedy via technology or social media? \_\_\_\_ No \_\_\_\_ Yes  
If yes, please answer questions 2a-2b:

2a) Please describe how and when you found out.

2b) Please share your reaction(s) to the way in which you first received the news.

Possible prompts: Was it helpful to receive the news in this way? (Any advantages to receiving the news this way?  
Any negative consequences as a result of receiving the news this way?)

**Question #3:** On a scale of 1-5, please describe how frequently have you used social media and/or technology to deal with illness, dying/death, or grief, with 1 = “Never” and 5 = “All the time”.

Never = 1 2 3 4 5 = All the time

How have you used these resources? (Possible prompts: To share memories? To seek support? To stay connected with the person who died – maintaining a continuing bond by updating him/her about current events, asking for advice, making amends, etc.? To gain information about coping with grief? Have you participated in digital survivor advocacy to prevent others from experiencing a similar loss? Other?)

What do you think influences your level of use of these resources? (Possible prompts: Access? Comfort with? Level of familiarity with how these resources can be used to cope with loss?)

How has the use of these resources been helpful? A mixed bag? Any negative experiences (Cyberbullying/trolling)?

**Question #4:** Has the use of digital technology or social media had an impact on your ability to have face-to-face conversations about sensitive topics? (When you use these resources, is it easier or harder to have face-to-face conversations with someone later?)

**Question #5:** Is there anything else that you’d like to teach me about how technology/social media has influenced the way you deal with loss?



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## CRITICAL DECISION-MAKING FOR ADOLESCENTS WITH LIFE-THREATENING ILLNESSES

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**Background, as it applies to adults.** One of the primary ethical principles guiding medical management is that of **respect**. Respect for the individual can be manifested by **autonomy**, allowing that individual the opportunity to make his or her own decisions regarding what happens to his or her own body. An adult is autonomous; he or she is capable, and legally authorized, to give consent for himself or herself, with regards to his or her medical care. There are certain situations, however, when an adult loses capacity to decide for himself or herself. Some examples of loss of capacity include severe illness with its consequent altered mentation, diminished awareness/diminished ability to process thoughts, and mental illness. Also, an example of an adult who *never* has possessed capacity to make his or her own decisions would include someone with serious intellectual impairment since birth. Each of these adults may be hampered in their ability to make self-determining decisions, but they may be able, with help, to make some limited decisions regarding their own health care. Depending on the reason for their limitation of capacity, their autonomy may vary with the passage of time. Thus, in the case of limited, or absent, autonomy, the ethical principal of respect calls for us to give **proper protections** to individuals who are particularly vulnerable.

Nancy Cruzan lost her ability to make decisions on her own behalf when she entered a persistent vegetative state as an adult in 1983. However, she had previously given to her family in verbal form clear and convincing evidence that she did not wish to be kept alive on life support devices if she ever were in a permanent medical crisis. This verbal **advance directive** was strong enough to direct the family and the Court to permit withdrawal of life support technology.

If an incapacitated adult has not previously exercised his or her autonomy by clearly giving an advance directives as Cruzan had, it is reasonable to rely on **substituted judgment**, that is, to rely on a determination made by a **surrogate decision maker** who knew the adult well, who knew his or her likes and dislikes, his or her philosophy and values in life, during his or her period of competence. Knowing someone's personality and life values is often helpful in providing direction with regards to how he or she would have wanted his or her health issues handled at this point in time.

But, if an adult has always been incapacitated since childhood, and has been unable to let his or her surrogate decision makers know his or her preferences, even by inference, then the Courts and family must seek guidance not only from the principle of respect, but from the other ethical principles of beneficence, non-maleficence, and justice, in the form of the **Best Interest Standard**. Joseph Saikewicz was an adult in 1977 who had been born with severe intellectual disability. He had never possessed capacity to make significant decisions with regards to his health care or to let his wishes be known. Instead, his mother had always been his surrogate decision maker and was officially appointed by the Court to be his legally authorized representative when Joseph became an adult. When Joseph developed life-threatening leukemia at the age of 67, his mother, as his legally authorized representative, was faced with some decisions to make. At that time, leukemia was treatable with radiation therapy and intravenous chemotherapy, but it only had a 30-50% remission rate. In order to receive treatment, Joseph would have had to make weekly arduous trips to the hospital, have IVs or central lines placed, be attached to IV pumps and tubing, all of which would require that he be physically restrained, causing him pain and fear. The side effects of the radiation and chemotherapy also would have been monumental and terrifying to Joseph, significantly diminishing Joseph's quality of life. Joseph's mother decided that the burdens of receiving treatment for his leukemia negated any benefit that might be incurred from the treatment, and that the burdens of *treatment* of leukemia were more significant than burdens of *living, and dying from,*



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leukemia. The Court ruled in favor of the mother's decision on behalf of her son in her quest for giving him the highest quality of life (utilizing the **Best Interest Standard**) for the time that he had remaining.

**Competence vs. Capacity.** We will use this preceding discussion of the ability of adults to decide for themselves as a backdrop for a discussion about who ought to make decisions with regards to children with life-threatening diagnoses. It has been said that children have never possessed capacity nor competence, and are, therefore, decision-incapable. Technically, **competence** is a legal term. An adult may be legally **competent** to make his or her own decisions even though he or she has just entered a coma. He or she will remain legally competent until the Court takes away his or her legal decision-making authority, and, ideally, assigns it to someone else (a legally authorized representative). **Capacity**, on the other hand, is an ethical term. Clearly, if someone is in a coma, he or she does not possess **capacity** for self-determination (even if the Court still allows him to make decisions). Someone with Alzheimer's disease with capacity that waxes and wanes throughout the day may have capacity to make some decisions in the morning but may lack capacity to make any decisions in the evening.

**Children's ability to self-determine.** By virtue of their age, children have never possessed legal **competence**. (There are a few exceptions, however, where children may actually possess legal competence, granted to them by the Court. This varies by state, and includes emancipated minors who are either married, are parents themselves, are self-employed and self-sufficient, or are serving in the military. It also may include Mature Minors.) Not possessing **legal competence** does not mean, however, that a child also completely lacks **capacity** for self-determination. Similar to adults with some restrictions in their capacities, children may have some limited ability to make decisions on their own behalf. Children who may have abilities to make informed decisions about their own medical care ("Mature Minors") include older children/adolescents, children who have already personally experienced illness and its medical interventions, children with higher levels of education, children with higher intelligence and with higher maturity of judgment. They may have some ability to understand the nature of proposed treatments and may be able to make decisions about risks and probable consequences of those treatments vs. risks and probable consequences of withholding treatment. They may have the ability to appreciate the risks and consequences to their own being of their decisions.

Children younger than approximately 2 years of age do not possess capacity to process important information to make decisions for themselves. Instead, their parents are counted upon to act in their behalf, based on the Best Interest Standard and based on the fact that the parents know the child, and know the value system in which he or she is being raised, and so can make determinations based on their parental surrogate decision-making authority. Parents are assumed to be the best decision-makers for their children due to the fact that they have the same values/religious beliefs as the child, if he or she were to grow to adulthood; they have the same culture as the child; they are best able to discern whether the child has pleasure or pain; they may have formulated goals/life plan for the child; they generally know what's best for their child; they know the child's wishes (if any) best. In one scenario, however, the parents may not be the best people to make decisions for their child. This situation would be that of child abuse causing a life-threatening injury to the child. The parental role is always to decide in the best interest of the child, considering likely harms/benefits of acute and chronic treatment, degree and duration of pain/suffering, anticipated subsequent quality of life/anticipated level of functioning, and expected duration of life. The parental *reasoning* in the situation of child abuse is more important than their actual *decision*. This is because, in the case of child abuse, significant conflicts of interest may exist. If the child is kept on life-support forever, the legal charge of "Assault" will never be changed to that of "Manslaughter" or "Murder," the latter of which have more severe penalties associated with them. In this situation, parents may be tempted to choose a plan of management of their child that minimizes punishment of the parent rather than the plan of management that protects the interests of the child. Protections against this type of conflict of interest may include utilization of the hospital ethics committee, hospital attorneys, hospital administrators, social workers, and religious/cultural leaders, and appointment by the Court of a *guardian ad litem* to make decisions on behalf of the child. Because of such risk of conflict of interest, in the case of child abuse, parental "autonomy" to choose for their child may fall second to the Best Interest Standard.



Children from about 2 years of age and older may have increasing capacity to understand the nature of their physical illness and to voice their opinions as to what interventions ought, or ought not, to be done to them. Asking children their opinions and allowing them the opportunity to assent or dissent from the decisions that their parents are making on their behalf is respectful, and is analogous to allowing an adult with some, but not complete, capacity to participate in his or her medical decision-making. The process of soliciting the child's wishes, and then carefully weighing all the options when critical decisions need to be made also demonstrates respect for the child as extra protections are sought for this vulnerable population. Where there is doubt or disagreement about a child's ability to self-determine, an ethics consultation may serve to allow all stakeholders to be heard and to mediate as necessary. An ethics consultation can help everyone to understand the medical facts, the contextual features (social, religious, cultural, values, economic, institutional, legal), any quality of life issues, and patient and family preferences and *the reasons for these preferences*. An ethics consultation can help to elucidate the best interests of the child and to sort out, ethically, what we "ought" to do.

Just as with sick adults who retain some capacity to decide on their own behalf, children may have some capacity to decide on their own behalf. As children age, develop more mature skills in analysis and reasoning, and are exposed to more experiences, they will naturally develop increasing capacity for self-determination. Generally, by adolescence, children are on the brink of possessing capacity to make decisions on their own behalf, equal to that of adults. Children who have had abundant experiences in dealing with chronic illness may be advanced in their abilities to weigh options and make decisions about their own health care, including decisions regarding palliative care, concurrent care, and treatment choices. Therefore, increased weight should be afforded the choices of these more mature minors who have advanced decision-making skills regarding their own health. Unlike their parents, they have personally experienced illness, so their wishes begin to take priority over the wishes that their parents have for them. Even though the adolescent's parents have legal authority to make decisions for their minor child, the adolescent may possess superior capacity to self-determine.

Ethics and the law may thus collide, making decisions difficult when there is an underlying patient disability, handicap, or severe illness; when consent/assent is required; at the end of life; and at the beginning of life. When an older child or adolescent has a life-threatening illness, all of these parameters may be met, thus requiring great care and sensitivity in making critical decisions.

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## ENGAGING ADOLESCENTS AND YOUNG ADULTS IN DECISION-MAKING

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The information in this article will build on the discussion in the previous article on Critical Decision-Making for Adolescents. The need for making difficult decisions in adolescents and young adults (YA) in the palliative care context generally occurs in the context of a new serious diagnosis, a change in prognosis, or a worsening trajectory of a condition or disease. In order for adolescents and YA to participate in decision-making, they need to be capable, be fully informed of all the pertinent information, and have advance care planning and decisional support tools and professionals to guide them. Appropriate documentation then aids in implementation of decisions.

### Elements of decision-making ability

- Cognitive capacity
  - Ability to comprehend information and understand the risks and benefits of possible interventions. This may be related to age, experience with disease, and cognitive ability.
- Emotional capacity
  - Voluntariness, courage, resolve. How influenced is the adolescent/YA by family and friends?
- Reasoning
  - Ability to make an informed decision consistent with one's personal goals and values. For instance, is there internal consistency with preferences and decisions?
- Social capacity
  - Degree of independence with respect to family and society. Can the adolescent/YA who chooses a specific treatment at variance with the family and community still have food, clothing, shelter, and treatment?
- Ability to communicate.
  - Can the adolescent/YA communicate his or her preferences verbally, or by other means such as art, storytelling, or play?

### Determining capacity

Legally competent young adults are competent until proven otherwise. Emancipated minors can generally make their own health care decisions. These include those who are living apart from their parents, married, pregnant and/or are parents. With the assumption that all minor adolescents should participate in decision-making to the extent that they are capable, how does one determine the level of capability?

**There are no tools to do this!** But there are some strategies to enhance assessment of capacity. (By the way, decision-making capacity is not the same as agreeing with the health care team or the family!)

Capacity is not necessarily determined by age or developmental stage. Children/adolescents with chronic illness have a higher degree of understanding of their condition and capacity than would be expected by age alone. Capacity may be considered "task related" in that a greater risk would warrant a greater degree of certainty. For example, allowing an adolescent to forgo a potentially life-prolonging treatment or request a high risk/high burden treatment requires higher certainty of their capacity. Capacity and ability to make decisions can be impacted by cultural influences, disease state, condition, and medications.

Be aware of characteristics of immaturity that are not surprising in adolescents such as changing goals and values, lack of interest and attention to the future, poor sense of identity, and/or a focus on body



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appearance. Should a low risk/high benefit treatment be declined because of the adolescent's fear of hair loss?

Strategies to assess capacity:

- Start a conversation
  - As you understand it, what is your medical problem/condition?
  - What are your concerns? Worries? What do you fear the most?
  - What do you think caused your illness/condition?
  - How do you think that your treatment is working?
  - What is most important to you as you deal with \_\_\_\_\_?
  - What are your hopes and goals with treatment?
    - Maximizing duration of life?
    - Health maintenance, minimizing pain and suffering, quality of life?
    - Maintenance of function and independence?
    - Being at home? Being with friends and family? Creating memories? Minimizing hospitalization?
    - Attending school? Participating in sports, arts or other activities?
    - Being at peace, minimizing anxiety, improving relationships?
  - What/who are sources of support as you make decisions? How do you see these people as being involved in your decisions?
  - Who/what helps you as you make difficult decisions?
  - Are there religious/spiritual/cultural values that help guide and support you in decision-making?
  - Under which conditions might your treatment preferences change?
  - Are there insurance/financial and/or logistical considerations?
- Respond to any questions honestly and in developmentally appropriate language. Be attentive to nonverbal communication.
  - As needed, use fairy tales, books, movies, play, drawings to further assess understanding and preferences.
- Review earlier decisions and assess for consistency.

### Engaging the adolescent/YA in decision making

To fully participate, the adolescent/YA should understand all the relevant available information concerning the nature of the illness/condition, and consequences of treatment or non-treatment options. Assure them that you will not lie. Review all potentially beneficial treatment options. Discuss risks and benefits if a treatment is used or not used. Include palliative care concurrent with disease-directed, life-prolonging treatment. Acknowledge areas of uncertainty. Disclosure actually supports hope and feelings of control, decreases anxiety, and facilitates participation in decision-making (Kushnick, 2010; Mack, 2018; Toce 2016). Dealing with the rare adolescent/YA who “does not wish to know” can be challenging (Korones, 2016).

In adolescents who are not legally competent and with many YA, decision-making involves the parents/legal guardians. Identify and include other decision makers. The shared decision-making model acknowledges that decisions concerning the adolescent/YA will affect all family members. The adolescent/YA and the legal guardian(s) should determine the definition of “family.” Family members have responsibilities to one another. Benefits and burdens of a decision should be determined for each member of the family. However, the adolescent/young adult with medical complexity has a special vulnerability. Seek informed parental permission when making decisions involving adolescents who are not legally competent. Accept a range of parental and adolescent involvement in decision-making—most parents prefer a shared decision-making model. In all cases, attempt to involve adolescents/YA with decisional capacity in making health care decisions to the extent that they wish to be involved.

Assent (free expression of willingness to undergo treatment):

- Ensure understanding of the illness/condition and consequences of treatment and non-treatment options



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- Assess capacity
- Solicit willingness to undergo treatment
- **Offer only medically and ethically appropriate options**
- Let them know if they do not have veto power!

Dissent (free expression of treatment refusal):

- Silent dissent may be demonstrated by non-adherence to treatment plan
- Considerations
  - Family cohesiveness
  - Level of maturity
  - Type of treatment including risks and side effects
  - Religious and cultural norms
  - Perceptions of illness and prognosis
- **If a minor adolescent is capable of assent, then he/she is capable of dissent**

There are many tools to assist in eliciting and documenting goals and treatment preferences (Toce, 2015). My recommendation is that this process includes a trained facilitator and/or member of the health care team, the adolescent/YA, and the family if appropriate. Pediatric advance care planning tools include:

- Voicing My Choices (Zadhey, 2015)
- My Wishes (pediatric version of 5 Wishes)
- Wishes (Fraser, 2010)
- My Choices (Noyes, 2013)
- Respecting Choices/FACE (Family/adolescent Centered advance care planning) (Dallas, 2016)
- Emergency Information Form for Special Needs Children from the American Academy of Pediatrics
- POLST (legal to some extent in at least half of the states)
- Durable Power of Attorney for Health Care and Advance Directive. This state-based document is pertinent for all those 18 and over and should be encouraged.

The conversation and advance care planning are very useful. However, with the exception of the POLST in selective states, they are not necessarily legally binding in adolescents who are not legally competent.

Conversations about future decisions and the role of the adolescent/YA should begin at diagnosis and initiation of treatment. The issue should be revisited frequently including during stability, when the trajectory changes, prior to hospital discharge, and during times of uncertainty. If you would not be surprised if the adolescent/YA died during the current episode of care or within 12 months, or if you do not know end-of life preferences, a conversation is mandatory. Advance care planning tools serve to engage the adolescent/YA in decision-making, elicit goals and preferences, and provide documentation.

## Resources

- AAP Committee on Bioethics. Informed Consent in Decision-Making in Pediatric Practice. *Pediatrics* 138(2), 2016: e20161484 *Very nice review.*
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- Midwest Bioethics Center Task Force on Health Care Rights for Minors. Health care treatment decision-making guidelines for minors. *Bioethics Forum*. 1995;11:A1-16. *Excellent basic review – over 20 years old but still pertinent!*
- **My Wishes**/Five Wishes <https://fivewishes.org/five-wishes/individuals-and-families/children-and-adolescents> (verified 10-18)
- Noyes J, Hastings RP, Lewis M, Hain R, Bennett V, Hobson L, Haf Spencer L. Planning ahead with children with life-limiting conditions and their families: Development, implementation and evaluation of '**My Choices**'. *BMC Palliative Care*. 2013;12:5
- **POLST** Legislative Comparison Chart (updated 4/18) <http://polst.org/wp-content/uploads/2018/08/2018.08.16-POLST-Legislative-Comparison-Chart.pdf> (Verified 10-18) *Includes "applicability to minors" by state. By my count, the POLST is specified as legal, at least to some extent, for minors. Many states require a signature by the parents/legal guardian.*
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## WHERE DO WE GO FROM HERE: ADVANCE CARE PLANNING & ADOLESCENTS

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Teens - we all know and love them! One minute they are showing you love and telling you the details of their day and in the next breath, they are rolling their eyes and protecting their information as if they have recently been trained by the CIA. Our teens with chronic illness are no different. But what does that mean for decision making? Many teens have shown us that they want to balance using their caregivers' direction while finding and being confident in their independent voice. So, when discussing advance directives with these soon-to-be young adults, clarity & modeling, permission & acknowledgement, and patience will all be incredibly important.

Voicing my Choices™ (VMC™), one version of an advance planning guide, was created as a focused guide for teens in response to specific feedback by adolescents and young adults on the already established Five Wishes™ tool. It was produced by the researchers at the Pediatric Oncology Branch, National Cancer Institute and the National Institutes of Mental Health at the National Institutes of Health and can be highly effective when given the right planning and thought.

Many of us are aware that in the healthcare setting, where these guides may be most relevant, time is also limited. Therefore, a clear introduction is important for both the teen & their family.

### Where to Begin?

There are multiple settings where a provider can present this idea of an advance care guide and there isn't a necessarily "right way." However, it will be important to remember that early engagement with these tools, when the teen isn't acutely ill, can help capture a more genuine picture. One option, if possible (and with the caregiver's permission), is to find space with the teen separate from their caregivers. There is often an unspoken pattern for teens to protect their loved ones from the more difficult conversations or thoughts they may be having. If they would like their caregiver present, encourage the parent to participate but without overpowering teen's voice. In this scenario, the teen clearly may find his or her parent to be a good source of support and it will be important for the provider to respect this space and encourage the parents to give their teen permission to discuss challenging topics.

### Be Direct:

VMC™ can be described as "a planning guide that we encourage all individuals—healthy, sick, young, old—to complete so that their loved ones know their opinions concerning their medical care now and in the future. There are prompting questions within this guide that can help each of us evaluate what is important to us and our overall goals of care if there ever comes a time we are unable to describe those wishes for ourselves." "Have you and your family ever thought about what would happen if you became sicker or had to be admitted again?"

When introduced to VMC™, our 16-year-old patient with Duchenne Muscular Dystrophy, proceeded to describe in detail the things he would and would not be willing to undergo. "Daily blood work—definitely not. Another hospital overnight—heck no." He brought the document home and continued to talk about it with his parents. He returned to the next clinic appointment with his "Jonny's Bill of Rights." These wishes may have gone unknown had conversation not been encouraged.



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## Modeling:

Especially for adolescents, one of the most effective ways to teach is through action. Have you as a provider ever filled out an advance directive? Would you know how you would answer if your teen patient asked how you felt about death? It can be helpful to tiptoe into an example with the teen: “One of these pages talks about what brings you comfort when you are sick. Do you have those people or comforting objects?” “Sometimes when I am having a bad day I like to be left alone—have you ever felt that way? Are there other things you can think of?” If they are engaged enough at this time to respond, ask permission to fill out those sections.

## Permission & Acknowledgement:

As important as it will be to ask for the teen’s permission to open and begin writing in VMC™, it will be equally important to acknowledge the challenging topics within the guide. This document is seldom completed in one sitting as it provokes much emotion and we should be thoughtful to give warning shots of the things you will be discussing. Give permission to stop at any point if they are feeling overwhelmed or take the document home to look over in the privacy of their home.

After quietly listening to part of my VMC™ intro, a 14-year-old patient of mine threw up one of her hands, gesturing to stop. She said, “I don’t want to offend you, because I like you as a person—you’re great, but do you know how many journals I have been given as a cancer patient? It won’t help me. I definitely don’t need to *process* anymore... but thanks.” When clarifying that it wasn’t exactly a typical journal and that there were prompting questions about her goals of care, she responded with “definitely, no.” She gave me permission to leave it with her mother. When her mother met me in the hall, she laughed at Jenny’s sass and blatant denial of the guide. I encouraged her mother to read the guide herself so that if Jenny began to ask questions, she would have other ideas on how to prompt more discussion. I reiterated that the paper itself didn’t necessarily need to be filled out and highlighted that it’s a tool to allow us to understand the patient’s wishes, thoughts, and concerns.

## Be Patient & Reengage:

The wonderful part about working on a multidisciplinary team is that any member can be encouraged to use this tool. While visiting Jenny later in the day, our fellow physician saw her mom reading the guide on the couch next to the patient. She said, “Oh wow, who gave you that? That guide is really helpful.” Jenny, even though somewhat resistant, engaged in the first few pages of VMC™ at that point. When she arrived at the page focusing on life support, she became visibly uncomfortable and needed a break. A few days later, Jenny opened up about death again. While we were watching ‘Hell’s Kitchen’ during an impromptu visit, she turned to me and said, “Well, how do *YOU* feel about death?” I explained that because of my job I have the privilege of talking to many people about their goals which has encouraged me to talk to my own family about my expectations. She told me she didn’t want to die and that “14-year-olds shouldn’t have to die,” but that she started talking to her mom about it more. “Have you two talked about where you would want to be if you knew you were sick and that there were no other interventions?” “I’m still hoping for a trial to come up. I’ve been thinking about those questions, but not ready to make a decision.” I reinforced what challenging topics these were, that there was no rush to making any decision, and that even if she made one, she is always able to change her mind. “Thanks.” And we went back to chatting about Gordon Ramsay and how he really needs to tone it down.

Despite the sensitivity and intensity of these conversations, there can be moments of levity, which we need to remember when it becomes overwhelming. These moments can be helpful in maintaining the relationship with patients and families. A young 12-year-old boy once told us that after he died he would like “his skull shrunk, put on a key chain, and given to my best friend.” Another young teen, very generously, asked for his reproductive organs to be donated. Another girl requested to be buried with her phone fully charged, and another to be buried with some of his Legos. Remember that the more often you use a guide like VMC™, the more natural it will begin to feel when bringing it into primary care conversations.





Your teenaged patients are looking towards many of you to give them the tools to manage their illnesses and this should be part of your team's routine. Be confident in your decision to discuss these challenging topics and allow your guidance to help develop their newly independent voices.

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## SUPPORTING SEXUAL HEALTH NEEDS OF ADOLESCENTS AND YOUNG ADULTS (AYAS) WITH CHRONIC ILLNESS

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### Abstract

Engaging in sexual activities is a normal and important aspect of development during adolescence and early adulthood. Despite the challenges of illness, adolescents and young adults (AYAs) with chronic illness report engaging in sexual behaviors at similar rates to non-ill peers. While not unexpected for this age group, AYAs with chronic illness also report high rates of engagement in risky sexual behaviors, which may confer additional risk for negative health outcomes within this population. To ameliorate such risk, it is essential for providers and parents to be informed about typical sexual development and illness-specific sexual health concerns in order to address the unique needs of each AYA in a supportive and sensitive manner. In this article, we discuss the prevalence of sexual behavior and risk-taking among AYAs with chronic illness, review normative adolescent sexual development, and provide developmentally-informed recommendations for communicating about and supporting AYA sexual health.

### Introduction

During adolescence and young adulthood, engagement in sexual behaviors is a common and normative aspect of development. However, risky sexual behaviors (such as unprotected sexual intercourse or having multiple partners) are also common among this age group (Cooper, Shapiro & Powers, 1998) and confer considerable risk for negative long-term health outcomes, including unplanned pregnancy and sexually transmitted infections (STIs). For adolescents and young adults (AYAs) with chronic illness, there is a common misconception that engagement in sexual behavior is less likely due to illness-related factors, and therefore risk of associated health consequences is minimal (Blum et al., 1991). However, research to date suggests that AYAs engage in sexual behavior at similar rates to their non-ill peers (Choquet, Fediaevsky, & Manfredi, 1997; Rosenberg et al., 2017; Suris, Panera, & Puig., 1996; Valencia & Cromer, 2000), if not more frequently (Choquet et al., 1997; Suris, Michaud, Akre & Sawyer, 2008; Suris & Parera, 2005; Valencia & Cromer, 2000). These data suggest that illness does not impair psychosexual development or exploration of sexual identity and romantic relationships. Rather, this developmentally appropriate and important aspect of adolescence is maintained or hastened (Tolman & McClelland, 2011).



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High rates of risky sexual behavior within this population are nevertheless concerning, as AYAs with serious illness are especially vulnerable to the potential negative health consequences of such behaviors. For these youth, an STI or unintended pregnancy may exacerbate existing health concerns, interfere with treatment, or pose additional long-term risks (Murphy et al., 2013; Sawyer, Drew, Yeo & Britto, 2007). Thus, to minimize risk and support healthy development of AYAs, it is vital for care providers and families to consider the sexual health needs of this population. Here, we will discuss the prevalence of sexual behavior and risk-taking among AYAs, review normative adolescent sexual development, and provide developmentally-informed recommendations for communicating about and supporting AYA sexual health.

**Sexual behaviors among AYAs with illness.** Research to date suggests that AYAs engage in sexual behaviors, including risky behaviors, at similar or higher rates compared with their typically developing peers. In a U.S. sample of AYAs on treatment for cancer, about 30% reported being sexually active with fewer than half endorsing consistent birth control or condom use (Rosenberg et al., 2017). In comparison, the 2017 Youth Risk Behavior Survey (YRBS) reported that 40% of U.S. high school students reported endorsed ever had sex, with 30% endorsing having sex in the past 3 months. Of these, 46% reported not using a condom and 14% reported not using any form of birth control (Kann et al., 2018). In a French national survey, 52% of male and 38% of female adolescents with a handicap or chronic illness (HCI) reported having had sex, compared to 42% of non-ill boys and 28% of non-ill girls (Choquet et al., 1997). Rates of sexual intercourse frequency, number of partners, and condom use were similar between HCI and non-ill groups, with the exception of HCI girls reporting higher rates of pregnancy, more use of oral contraceptives, and more partners more often compared to non-ill girls. Similarly, across a range of chronic conditions, studies of European AYAs have reported similar age of first intercourse, frequency of intercourse, and use of contraceptives compared to non-ill controls (Suris et al., 1996; Suris & Parera, 2005), with one study reporting higher rates of early sexual debut and higher likelihood of engagement in multiple risk behaviors (Suris et al., 2008). Thus, having a chronic illness does not appear to affect likelihood of sexual behavior engagement among adolescents, and in fact may confer higher risk for some risky sex practices.

**Considering “risk” associated with AYA sexual behaviors.** To understand the sexual health needs of AYAs, it is important to consider adolescent sexual behavior in developmental context. First, engaging in sexual behaviors is a normative and expected aspect of adolescent development, as adolescents develop a psychosexual identity and explore romantic relationships (Brooks-Gunn & Furstenberg, 1989; Tolman & McClelland, 2011). In recent decades, research in this domain has shifted from primarily focusing on potential risks associated with adolescent sexuality to examining potential positive experiences and consequences as well (Halpern, 2010; Tolman & McClelland, 2011). Thus, similar rates of sexual activity between AYAs and their non-ill peers suggests that, for most AYAs, illness does not prevent or delay these important and potentially beneficial developmental processes from unfolding. Second, engaging in risk behaviors is also typical in adolescence, including substance use, law-breaking, and risky sexual practices (DiClemente, Hansen, & Ponton, 2013), so much so that to some degree it can be considered a function of normal development (Steinberg, 2008). As many AYA researchers have hypothesized, disparate psychosocial outcomes experienced by AYAs may be in part attributed to illness disrupting critical developmental tasks of adolescence (Bleyer, 2007; Morgan et al., 2010; Zebrack & Isaacson, 2012). From this perspective, rates of sexual behavior engagement and even risky sexual behaviors among AYAs may be considered an indicator of resilience: despite the challenges of illness, AYAs are continuing to engage in expected and age-typical behaviors, including risk-taking, as they navigate the developmental tasks of adolescence.

While being normative for this age range, AYA engagement in sexual risk behaviors is a concern given the increased likelihood of associated adverse health consequences for this population (Sawyer et al., 2007). One such concern is increased susceptibility to STIs and their sequelae. For example, common STI infections such as chlamydia or gonorrhea may interfere with the effects of chemotherapy for AYAs with cancer (Bavinck & Berkhout, 1997). For patients with compromised immune systems, STIs and their treatment may delay other disease-directed regimens and/or increase the risk of serious medical complications like sepsis or disseminated viral infection. Additionally, STIs may also confer longer-term risks. Genital human papillomavirus (HPV), the most common STI, has been identified as causing cervical and other HPV-related cancers. Among survivors of childhood cancer, risk of developing HPV-related



malignancies in adulthood is considerably increased relative to peers, especially for those previously treated with radiation therapy (Dores et al., 2002; Neglia, 2001). AYAs may also encounter health complications due to unintended pregnancy resulting from lack of or improper contraception use. AYAs receiving cancer treatment are exposed to multiple teratogens (i.e., chemotherapy drugs, radiation) as a part of treatment, which would have severe effects on a developing fetus (Meirow & Schiff, 2005). Hence, pregnant young adults receive alternative, less-effective treatment regimens. Thus, given these risks, increased prevention and intervention efforts specific to this population are needed.

**Talking to AYAs about sexual behaviors.** Integrating sexual health discussions into standard care for AYAs may aid in preventing negative health outcomes associated with sexual risk behaviors. Currently, many AYAs with chronic illness do not receive sufficient information about sex education and reproductive health from their providers, including information about contraception use and other safe sex practices (Murphy et al., 2013). Misconceptions and lack of knowledge about sexual health issues specific to AYAs, such as young people with cancer assuming they are infertile (Partridge et al., 2004), may contribute to engagement in risky behaviors. Such discussions are needed to provide AYAs with both general sex education as well as information about how their specific condition may affect their sexual health. For example, experts emphasize that comprehensive discussions of AYA sexual health must include normal developmental *and* cancer-specific sexual health education, including information about susceptibility to STIs, interactions between oral contraceptives and chemotherapy drugs, and fertility issues (Murphy et al., 2013). Ultimately, sufficient discussion and education about sexual health as it pertains to the unique circumstances of each AYA is a needed first step toward prevention.

Providers should also consider that AYAs may not initiate conversations about reproductive health (Bolte & Zebrack, 2008). While studies have shown that adult patients (including AYAs) believe discussions about sexual health with providers are important (Flynn et al., 2012), other studies of AYAs specifically have found that few endorse an interest in such conversations (Rosenberg et al., 2017). AYAs may not feel comfortable asking questions or disclosing their sexual history to their provider. Some may have concerns around confidentiality or discussing issues related to sexuality with parents or family members present. Thus, it should not be the responsibility of the patient to initiate conversations about sexual health or ask the necessary questions. Instead, as recent commentaries have emphasized, providers should be informed about adolescent development as it relates to sexuality, and discussions of both general and disease-specific sexual health education should be integrated into standard care (Murphy et al., 2013; Sawyer et al., 2007). Providers should be prepared to initiate such conversations, navigate issues around confidentiality and parental consent, and be cognizant of diversity during such discussions (i.e., cultural issues, sexual orientation; Bolte and Zebrack, 2008). Table 1 provides specific communication strategies for initiating supportive conversations, normalizing and validating experiences, providing individually-relevant information, and asking appropriate questions.

Parents can also play a role in supporting AYAs in their sexual health. Developmental literature has identified family factors that are associated with reduced sexual risk-taking, including parent-child closeness and parental supervision and monitoring (Huebner & Howell, 2003; Miller, 2002; Regnerus & Luchies, 2006). These factors have been argued to protect against risk due to parents being able to more effectively communicate values regarding adolescent sexuality to their child when they have a close, supportive relationship and monitor their child's activities (Miller, 2002). Akin to providers, parents should become informed regarding adolescent sexuality, including an understanding of what is typical and expected for adolescents as well as sexual health issues that may be unique to their child (i.e., illness-specific concerns). Being knowledgeable about such information may help parents have supportive conversations with their AYA children about sexuality and aid in their sexual health education.

**Summary.** Ultimately, addressing sexual health needs of AYAs with chronic illness requires walking a delicate line. Given the potential for negative health consequences, preventative efforts are needed to reduce rates of risky sexual behavior within this population and promote wellbeing. However, it is important for providers and parents to approach these issues with awareness and sensitivity to the unique needs of AYAs, who are seeking to maintain normality and engage in the same behaviors as their peers. It is thus paramount to support these youth in navigating their sexual development by providing sex education and regular opportunities for discussion about their specific sexual health needs, while



acknowledging that illness does not and should not preclude them from engaging in this normative and important aspect of development.

**Table 1. Communication Strategies for Parents and Providers**

Initiating Supportive Conversations	Normalizing & Validating Experiences	Providing Individually-Relevant Information	Asking Appropriate Questions
<p>"I'd like to talk to you about ways to make sure you're staying safe and healthy when you are engaging in sexual activity. Is that okay with you?"</p> <p>"Can we take a few minutes to talk about your sexual health? I'd like to share some important information with you and answer any questions you have."</p> <p>"So that I can take care of <i>all</i> of you, it is important that I know about <i>all</i> of your identity. What is important for me to know about your [sexual identity/sex life]?"</p>	<p>"It's normal for [teens/young adults, as appropriate for patient] to be thinking about or having sex."</p> <p>"Sometimes [teens/young adults, as appropriate for patient] don't feel comfortable discussing or asking questions about sex, and that's okay. It's my job to talk about it so I can help you stay healthy."</p> <p>"Other [teens/young adults, as appropriate for patient] with [illness] have told us they'd like to be given more information about how their [illness/treatment] can affect their sexual health. Is it okay if we talk about that?"</p>	<p>"It's important for everyone to use condoms to prevent STIs, and it's additionally important for young people with [illness]. Getting an STI or becoming pregnant could interfere with our ability to treat your illness because..."</p> <p>"Sometimes young people who've had [illness] might think that they are infertile and don't need to practice safe sex. Have you ever wondered about that?"</p>	<p>"What does the term 'sexually active' mean to you?"</p> <p>"Are you attracted to men, women, or both?"</p> <p>"How would you describe your own sexual identity?"</p> <p>"Is there anything you are worried about regarding your sexual health?"</p> <p>"How has your [illness/treatment] affected your sexuality or romantic relationships?"</p> <p>"Is there anything you'd like to know more about or any resources I can give you?"</p>

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## READERS' CORNER

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### “Bad” vs. “Unexpected” News: How you frame it matters!

When Bad News Isn't Necessarily Bad: Recognizing Provider Bias When Sharing Unexpected News.  
Carissa Carroll, Christopher Carroll, Naomi Goloff, Michael B. Pitt  
*Pediatrics* 2018, 142 (1) e20180503; DOI: 10.1542/peds.2018-0503

**Abstract:** As providers, we are often part of difficult conversations in which we have to share bad news with families. Increasingly, this skill is being recognized as a necessary competency for effective clinical practice, with curricula and protocols emerging to support training in this art of breaking bad news. In parallel, we are learning more about the role implicit bias plays within our health care encounters, in which our lived experiences provide a lens through which we approach all interactions and unconsciously shape our understanding and behavior.

In this article, we will share a family's journey that highlights where these two concepts (breaking bad news and implicit bias) often intersect. Our purpose is to shine a light on an important lesson for providers: that often we bring our own biases to the table when we frame news as “bad” when ultimately, from a family's perspective, it may not be bad at all. In doing so, we may play an integral role in how we start a family's journey with a new diagnosis. Using one family's story as a framework, we aim to help providers consider when an alternative paradigm may be valuable, with a shift from “breaking bad news” toward “sharing unexpected news,” and we provide tangible skills to consider when this approach may be ideal.

**Who** is the audience for this information? While I think that this is aimed at health care providers initiating difficult conversations, this will be welcome by parents and family members. It encourages both groups to be open to reframing their outlook.

**What** is special about this article? Interestingly there is a video abstract supporting this information. The authors emphasize that this important conversation and the words that you use will be part of the family's story FOREVER, and that the role of delivering this sensitive information should be taken seriously. There are some very helpful strategies to use in framing unexpected news and information on things to avoid.

Our editor, Chuck Corr, PhD, noted that this article reminded him of the essay “Welcome to Holland” written by E.P. Kingsley in 1987 about raising a child with Down syndrome. You might fantasize about the pregnancy experience being one thing, such as a fabulous trip to Italy, but then find that you have landed somewhere totally unexpected such as in Holland. “But...if you spend your life mourning the fact that you didn't get to go to Italy, you may never be free to enjoy the very special, the very lovely things...about Holland.” The essay is available on the National Down Syndrome Society website: <https://www.ndss.org/resources/a-parents-perspective/>

**Where** and how can I apply this information? This concept of reframing information in the hopes of avoiding bias can be integrated into health care providers mode of communication. The strategy should be taught in medical and nursing schools. Parents welcome this information. “Welcome to Holland” is posted on the National Down Syndrome Society website and has been overwhelmingly well received. There could be endless applications such as giving survival rather than mortality data or trying to find positive or less negative aspects of seemingly bad information. This has made me think intensely about all that I learned about how to “deliver bad news.” Perhaps I need to reframe and neutralize that thought...



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- *When Your Child is in Pain*
- *Talking With Your Child About His or Her Illness*
- *Talking to Your Child's Doctor: When Your Child Has a Serious Illness*
- *When a Child Dies: A Guide for Family and Friends*
- *Helping Children Cope with the Loss of a Loved One*

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- *Nonpharmacological Pain Management for Children*
- *Sibling Grief*
- *Pediatric Pain Management Strategies*
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Creative Therapies Toolkit developed by **PA Pediatric Palliative Care Coalition**. This resource is for caregivers and families. <http://www.ppcc-pa.org/creative-therapies/>

*Clinical Practice Guidelines for Quality Palliative Care, 4th edition*, create a blueprint for excellence by establishing a comprehensive foundation for gold-standard palliative care for all people living with serious illness, regardless of their diagnosis, prognosis, age or setting. <https://www.nationalcoalitionhpc.org/hpc/>

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- [\*\*Deep In the Weeds: Medical Marijuana and Pediatric Palliative Care\*\*](#)  
Thu, December 6, 2018  
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Education Programs and Preconference Seminars: April 13-14, 2019  
Main Conference: April 15-17, 2019  
Marriott Wardman Park Hotel, Washington, D
- **NHPCO's Interdisciplinary Conference** Preconference Dates: November 2-3, 2019; Main Conference: November 4-6, 2019 - Gaylord Palms Resort and Convention Center, Orlando, Florida

### Journal/News Articles

- **How to Make the Case for Pediatric Palliative Care:** On the blog, CAPC's pediatric program manager, Alice Stafford, highlights insights from these conversations, in the hope of equipping programs with the skills needed to demonstrate the value of building and maintaining a successful program. Read more [here](#).
- **Pediatric advance care planning linked to better understanding of child's end-of-life care choices:** The more that families understand the end-of-life treatment preferences expressed by adolescents living with human immunodeficiency virus (HIV), the less likely these youth are to suffer HIV-related symptoms compared with youths whose families do not understand their end-of-life care goals, according to a single-blinded, randomized study published online Oct. 19, 2018, in *Pediatrics*. And when families struggle to understand their child's end-of-life care choices, that is associated with a higher likelihood of HIV-positive adolescents suffering physical symptoms, including pain. Read more [here](#)

**Subjects and Contributors for Future Issues of This E-Journal** For upcoming E-Journal issues, we plan to address issues related to adolescents and young adults. If you know of good topics and/or contributors (including yourself) for these and/or other future issues of this e-journal, please do not be shy! Step right up and contact Christy Torkildson at [ctorkildson@mail.cho.org](mailto:ctorkildson@mail.cho.org) or [christytork@gmail.com](mailto:christytork@gmail.com); or Chuck Corr at [ccorr32@tampabay.rr.com](mailto:ccorr32@tampabay.rr.com). We will work with you!

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